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## Online "Superusers" as Allies of the Health Care Workforce

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Health systems around the world are grappling with how best to provide high-quality care to the growing numbers of people now living with one or more long-term conditions, while at the same time bending the health care cost curve. Policy attention has thus far centered on three approaches: restructuring health care (with emphasis on primary care, population health, and accountable care organizations), supporting financial reform (for example, moving from fee-for-service to capitation- and value-based models), and encouraging greater personal responsibility for prevention and care through policies designed to encourage self-management.

We believe that online health communities of people with chronic conditions, such as asthma, cystic fibrosis, and diabetes, have a major role to play in promoting illness self-management. Furthermore, we contend that the "superusers" of these communities are particularly important in realizing their potential.

### Online Health Communities

Online communities are groups whose members interact with one another primarily via the Internet. Over recent years, the rise of social media and the emergence of major online platforms, from Facebook to Twitter to HealthUnlocked (which hosts hundreds of health communities), have exerted a fundamental impact on people's attitudes, decisions, and behaviors, including their experience of health and illness. On average, one in four Internet users with long-term conditions go online to find others with similar health concerns.

*Key to the success of these forums is the emergence not only of a critical mass of active users who help the community thrive and self-regulate, but also of a select minority of users — the superusers — who keep the community engaged and cohesive over time."*

There is emerging evidence that online peer-to-peer support can enhance disease self-care, reduce health care utilization, and improve a variety of health outcomes that may also result in both direct and indirect health care cost savings. For example, it has been suggested that online peer support can increase smoking abstinence, and online social interactions are associated with a lower risk of assorted critical health problems.

Having studied these digital communities for several years, particularly forums of people with asthma and other chronic respiratory problems, we recognize the considerable potential that online discussion groups can have in helping individuals deal with the day-to-day complexities of living with long-term conditions and navigate health systems. For example, connecting with others facing similar diagnoses can provide quick, easy, and often anonymous access to emotional support, information based on others' personal experiences, and resources that sufferers may need to manage their illnesses — a form of health literacy.

### **Superusers = Digital Hubs**

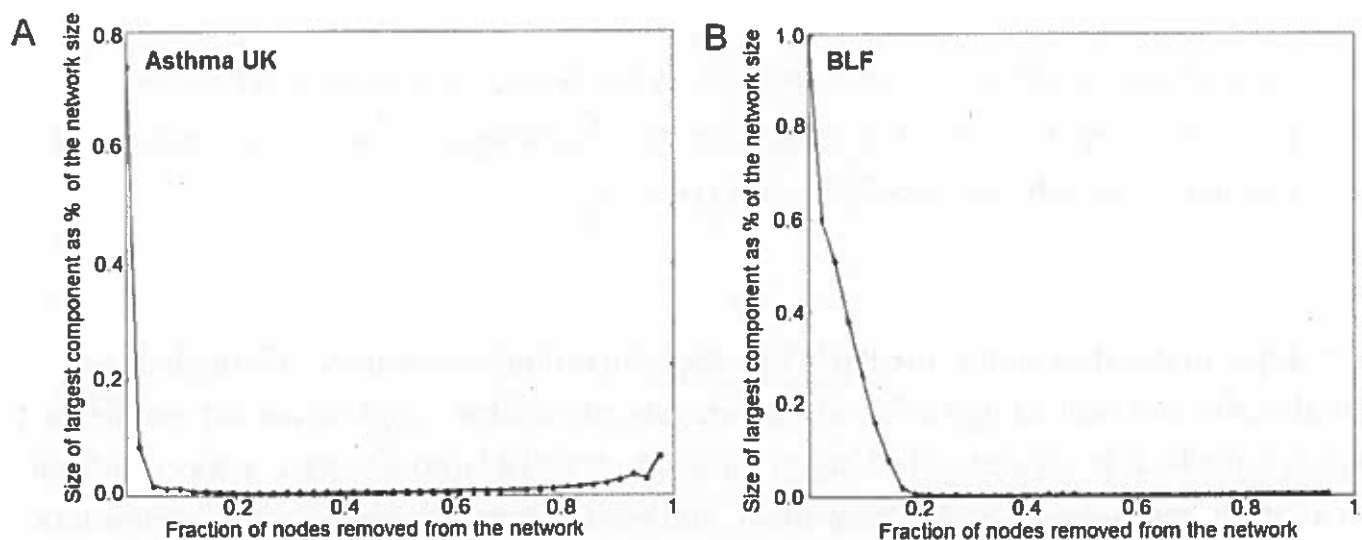
Key to the success of these forums is the emergence not only of a critical mass of active users who help the community thrive and self-regulate, but also of a select minority of users — the superusers — who keep the community engaged and cohesive over time. Superusers are defined as individuals who are disproportionately active in online health communities, representing the top 1% of all active users based on the number of contributing posts. They are typically lay volunteers who spontaneously emerge as communities grow larger. They play a central role in generating content, spreading information, facilitating discussion and connections, and providing support, advice, and direction to other members.

*Modeling the targeted removal of users, starting from the most connected ones (i.e., superusers), induced the two networks to quickly collapse. Ten superusers can sustain a community of 1,000 users."*

Superusers are recognized as valuable resources. Through their constant online presence, these change agents will, for example, work to ensure that new members connect with more established users, that discussions do not run dry, and that egregious online behaviors are promptly stopped. Superusers can, indeed, be seen as fundamental to the effective functioning of a large network.

In our recent analysis of two online communities for patients with chronic respiratory conditions, hosted by Asthma UK and the British Lung Foundation, we found that modeling the targeted removal of users, starting from the most connected ones (i.e., superusers), induced the two networks to quickly collapse. Ten superusers can sustain a community of 1,000 users.

## Collapse of Two Online Health Communities as a Result of the Removal of Users, Starting from "Superusers."



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We have come to see superusers as potentially strong informal allies of the health system. Our research suggests that superusers, through their role as volunteer network hubs, can contribute to the cost-effectiveness of online peer self-management support systems, especially those designed for patients with long-term conditions.

We argue that strategically investing in, and strengthening, the currently informal peer-to-peer sector has the potential to significantly help improve health and reduce the burden on health care providers and systems. Peer-driven online health communities and their embedded superusers are poised to become an integral and powerful component of the health care ecosystem and to exert growing influence within traditional professional-driven health care

models. However, shaping this more inclusive model will require new policies and a broader conception of the professional-driven health care team.

## Road Map for a New Model

To realize our vision of superusers and digital communities as allies of the health care workforce, we propose three targets.

### ***Target 1 — Support the growth and integration of patient-driven online health communities.***

Considering the Internet penetration rates worldwide, online health communities could play a potentially important role in improving health and the sustainability of health care systems globally (e.g., by partly meeting the increasing demand for health care services).

*Strategically investing in, and strengthening, the currently informal peer-to-peer sector has the potential to significantly help improve health and reduce the burden on health care providers and systems."*

An example in this direction is the Big White Wall, an online community offering help for mental health and well-being issues, such as anxiety, depression, and relationship problems, to users in Canada, New Zealand, the United Kingdom, and the United States. Services include peer support, resources for self-management, and online therapy with registered counselors. As a result of the U.K.'s innovative health care policies, the Big White Wall now offers free access to active military personnel and their families and to some patients through the National Health Service and other providers.

Evidence from large-scale surveys indicates that about 70% of the respondents felt better in at least one domain. Big White Wall members remain anonymous to the moderators, who cannot provide any diagnostic assessment or clinical treatment. This makes the health care model underlying this online community distinct from traditional health care systems.

There is growing evidence that online services like this have produced significant improvements in users' self-management outcomes. Policies are therefore needed to enable similar models of self-care to be extended to long-term conditions beyond mental health. This target could be achieved by integrating traditional health care systems with online platform services, nonprofit organizations, and the charitable sector — currently the main providers of online peer support.

## **Target 2 — Recognize and support superusers.**

The health care system needs to acknowledge and enhance superusers' central role in sustaining online health communities. A model that explicitly relies on superusers and digital networks for promoting self-management could be seen as an extension of British Expert Patients, a group intervention program that is led by trained lay members to build self-care skills in people with chronic diseases.

In this integrated model, health care professionals encourage users' engagement with online health communities and their superusers. Identifying users who have the potential to become superusers, though, can be difficult. Health care leaders and providers should consider developing programs aimed at training superusers with a view to effectively working with them.

## **Target 3 — Develop robust evaluation systems for superusers.**

New systems are needed to evaluate models of online self-care in terms of participants' use of formal health care services and their health outcomes. These new evaluation systems must properly account for the exponential impact of superusers' online activity on health behaviors and outcomes, not only of the contributing members of health communities, but also of "lurkers" who simply read messages without joining discussions. Online social network effects are largely neglected in current cost-effectiveness analyses.

*Considering the Internet penetration rates worldwide, online health communities could play a potentially important role in improving health and the sustainability of health care systems globally."*

As superusers become more active online, and as they gain prominence and even set norms in health communities, independent assessments are needed to identify risks they might pose to other users — such as being overly judgmental — and to establish safeguards to prevent abuse, such as the spread of "fake" medical news. We therefore recommend that policy advisory boards of health care organizations include network science experts, who study complex social and technological systems.

Online health communities, led by their superusers, represent a powerful and largely untapped resource to support people in effectively self-managing their long-term illnesses. Innovative policies are now needed to enable the integration of online health-related networks with traditional health systems and social care networks (e.g., support groups, families, and social

circles). This integration must build on partnerships between health care services, the charitable sector, and Internet platform providers. This consumer-driven health care model has the potential to dramatically impact the effectiveness, sustainability, and scalability of self-management support systems and improve health outcomes for people living with chronic conditions.

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